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TESTIMONY BEFORE THE PUBLIC HEALTH COMMITTEE IN OPPOSITION TO RAISED BILL NO. 88
AN ACT CONCERNING AID IN DYING FOR TERMINALLY ILL PATIENTS

Co-chairs Abrams and Steinberg and members of the Public Health Committee:

I believe in choice and in bodily integrity. The choices I have believed in included the right to choose the manner of one's death. To be able to say that "enough is enough." To be able to choose to end one's suffering. Nothing seemed clearer. But then I had Second Thoughts.

I have been a Civil Rights Lawyer for almost 40 years. In 1995 I began to develop a specialty in Disability Rights. In 2000 I became the Managing Attorney at the State of Connecticut Office of Protection and Advocacy for Persons with Disability, and from 2017 until my retirement in 2018, I was the Legal Director at Disability Rights Connecticut.

In 2010, I worked on a case that helped me understand how Physician Assisted Suicide can result in the untimely and unnecessary death of people with disabilities who otherwise could live productive and fulfilling lives. The disabled people I represented were challenging an attempt by doctors to be exempted from State laws regarding prosecution for prescribing lethal doses of drugs to patients the doctors judged to be terminally ill and who asked for drugs to take their own lives.

I learned of individuals with significant disabilities who, while not terminally ill, could not find a way to live outside of a long-term care institution, and chose to stop receiving food and hydration or to have life support equipment disconnected. I learned that Physician Assisted Suicide removes the impetus for doctors to treat situational depression, to develop better palliative care, and to find innovative ways to help people become independent so they do not feel like death is their only option.

For a person with a significant disability to live independently, it takes knowledge about assistive technology, employee management skills for dealing with personal care assistants, familiarity with human service and health care systems, and the expenditure of considerable effort. Few physicians have this skill set. Oftentimes, it is a battle for disabled people to receive the same standard, aggressive treatment for their illnesses that people without disabilities receive.

Case in point: I represented a 15-year-old with intellectual disabilities who was diagnosed with a treatable form of leukemia. The physicians said he should not be treated because he would not be able to understand why he was “suffering” from the side effects of the chemotherapy, and the radiation might cause him to lose additional cognitive function. They decided that his life would no longer be worth living, and the hospital’s ethics committee concurred. After OPA’s intervention the young man was treated, went into remission, and was adopted into a loving family.

When doctors operate under the assumption that people with significant disabilities are “suffering,” an early death can begin to look reasonable. I began to understand that permitting Physician Assisted Suicide would discourage doctors from thinking of people with disabilities as having a life worth saving. If Connecticut physicians are permitted to end lives, people with significant disabilities will be vulnerable because often they don’t want to be a burden on society and are deferential to physicians’ knowledge.

The papers I filed in 2010 taught me that “Disability advocacy groups know that among health care providers, the distinction between disability and ‘terminal disease’ is often more a matter of perception than objective diagnosis. For example, the various manifestations of muscular dystrophy, multiple sclerosis, or any number of other chronic conditions may be considered by some to be progressive disabilities, while others see them as ‘terminal diseases’. Some people are born with disabilities that involve multiple, complex medical issues or genetic syndromes that can, but do not always, result in shortened life expectancies. Other people with physical disabilities may experience repeated, life-threatening infections or various other serious health issues. Some even depend on life-support technologies, such as respirators or dialysis, or receive nutrition and hydration through feeding tubes and central line catheters. It is not clear at what point these people would be considered ‘terminally ill’ or how much such decisions would be influenced by pervasive stereotypes about ‘quality of life’ and frank ignorance about the possibilities of living a good life with a disability.” See Affidavit of James D. McGaughey, *Blick v. Office of Criminal Justice*, NO: HHD CV 09 5033392 S, Superior Court, Connecticut, 2010.

I have thus changed my position. I no longer support what is euphemistically called “Death with Dignity.” I see it as a dangerous option that devalues the lives of people with disabilities and will lead to eugenics. I have incorporated this into my personal life. My advanced directive no longer permits early termination of life support. Life is valuable. Let the State of Connecticut celebrate this, and defeat Physician Assisted Suicide, Raised Bill No. 88. If we don’t do it now, it may be too late for Second Thoughts.